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# VOICES of SSAN

September 2019 Volume 18

## Meet the New CFILC SSAN Member

**Renee Wooten**



### By Renee Wooten

Hi, my name is Renee Wooten, I am the new California Foundation for Independent Living Centers (CFILC) Representative to SSAN. I am a volunteer with the DO Network which is a program within CFILC. Originally, I am from Minnesota, and moved out to California when I was 19 because I was ready for a change. I have three surviving sons with various disabilities. My oldest son has an auditory processing disorder and shows signs of Autism, my middle son has autism, and my youngest son has ADD. While I was married, I took on the responsibility of caring for my step son with Cerebral Palsy, **(Continue on page 2: "Renee")**

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Check out the Statewide Self Advocacy Network (SSAN) webpage at [www.scdd.ca.gov/selfadvocacy](http://www.scdd.ca.gov/selfadvocacy)



SSAN Newsletter Editor -Robert Levy

### Contributors to this edition:

- |                    |              |
|--------------------|--------------|
| Renee Wooten       | Paul Mansell |
| Wesley Witherspoon | Robert Levy  |
| Nicole Patterson   | Kecia Weller |



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along with other developmental disabilities, who unfortunately, passed away at the age of 23, but is still a very important part of my life. I am excited to bring a unique perspective to SSAN as both a self-advocate and a parent advocate. I am a second-generation parent with a disability.

Most of my advocacy experience has centered around advocating for services for my sons and I finally feel that I am in a place to advocate for others and work towards changing the system. I am a survivor of domestic violence and am very interested in working on exploring the intersectionality between people with disabilities and sexuality. Over the last year, I have had the opportunity to tour WEAVE (is the primary provider of crisis intervention services for survivors of domestic violence and sexual assault in Sacramento County) to assess the accessibility of their building.

I am excited to be a part of SSAN and explore the next chapter of my advocacy.

## **People First of California Statewide Gathering**

**By Nicole Patterson**



**Happiness GO FOR IT!**

**Event Date:** June 7<sup>th</sup>-9<sup>th</sup>

**Location:** DoubleTree Hotel,  
Sacramento

**Conference Theme:** “Happiness: GO FOR IT!”

The 2019 People First of California Statewide Gathering had about 250+ people. It seemed that all participants had fun learning something new, enjoyed seeing old friends and meeting new ones.

On June 7<sup>th</sup>, Friday night, the Early Birds Band did several songs to get people ready for the kick-off ceremonies.

On Saturday, June 8<sup>th</sup> after breakfast, there was a keynote by Rebekah Amick. She talked about being in an abusive marriage and how she found the support that she needed to remove her boys and herself from that unhealthy situation. She also talked about how she and her boys were able to work towards their road to happiness.

**(Continue on page 3: “PFC Gathering”)**



**(Continued from page 2 “PFC Gathering”)** After the keynote on Saturday people had the option to go to sessions. The first session topics were Self-Determination, Real Relationships with People First, How to Stay Happy, and Employment Project. I led the session on Self-Determination and it went well.

The second session was held for self-advocates with Michael long talking about the People First Public Speaking Guide. There was also a session that was directed towards people who support People First advocates called Something for the Professionals.

The third session topics were Loving Myself Before Finding Love from Others, Stop Bullying, People First Voting Project, and Finding Happiness. I attended the People First Voting Project. I thought this voting session was very well presented. Here are some points that I learned from that session:

- You can register to vote as young as 16 years old.
- You don't have to show your ID at the polling place. They just need to verify your name and address.
- You have the right to ask for curbside voting.

- You can now register to vote on Election Day, but if you do it this way you will not be able to vote for your local candidates.
- You don't have to choose a political party, but you will not be able to vote in the primaries if you haven't chosen a party.
- You can vote at home through absentee ballot.
- You **can't** vote in prison, jail, or if you're on parole.
- You **can** vote if you're on probation.
- Before you vote for candidates make sure you know what they believed in so that their beliefs match yours.
- Nobody can tell you how to vote. You must decide.
- The person helping you vote can help you understand what is on your ballot, but they cannot tell you how to vote.
- If you're conserved, you can still vote unless a judge says you can't.
- Make sure you re-register when you move. You can also call and find out where your voting place is.

The Voting Project can help you register and understand the ballot.

**(Continue on Page 4: “PFC Gathering”)**



## **(Continued from page 3: “PFC Gathering”)**

They have trainings and sessions available. In October, voter information webinars will be held to talk about what's on the ballot. You can check online at: [www.wecarealot.org/vote/](http://www.wecarealot.org/vote/)

The Gathering also had Meet a Friend. This was something like speed dating, but for meeting friends. At the annual awards dinner Saturday evening, Tom Hopkins from the Capitol People First received the Advocate of the Year award. The Professional of the Year award went to Pierce Welch, who owns Pierce Enterprise, the company that supports People First of California by making their gathering t-shirts every year. I can't forget about the dance, movie night, and a selfie booth.

On Sunday, June 9<sup>th</sup> was the closing ceremony, open mic, and raffle.

## **UC Davis Panel Presentation Updates**

**By Robert Levy**

Recently, I was a part of 2 different panel talks at the UC Davis MIND Institute. The first presentation talk was on Self Advocacy, it was held on Monday, May 6, 2019, here at the UCD MIND Institute. Myself and two other self – advocates talked about our journeys through our lives from our childhood experiences to our present experiences and what are the plans for our future. The panelists were given the questions so that we could answer them. The second presentation talk was called RISE UP, and it was held on Friday, June 28, 2019 here at the UCD MIND Institute UCEDD. The panel included me and 3 other self-advocates. This session was about sharing your experience about having a disability or caring for a family member with a disability.

At the second panel talk, we answered two main questions:

- What are some important things that you think the

**(Continue on Page 5: “UCD MIND”)**

**(Continued from page 4: “UCD MIND”)** next generation of healthcare providers should know about caring for a person with autism and supporting their family?

- How can we better reach people who do not know about autism and support services?

In the panels, we shared our diverse cultural experiences (language, ethnic background, groups we are affiliated with), along with our family experiences and the professionals that have supported us in our lives. We talked about if any of these experiences made it hard for us to access our health or other care and, if so, how does it work for us.

In the panels, we also talked about what are some important things that we thought that the next generation of healthcare providers should know about caring for a person with autism and supporting their families. We talked about how can we better reach people who do not know about autism. We also talked about the support services that we need to help us have a productive life. Having the right support means we won't become segregated

and can live in the community. People with disabilities deserve to be included and be equal as everyone in our society who doesn't have a disability.

## **The 24<sup>th</sup> Annual California Statewide Self-Advocacy Conference**



The Conference was Friday and Saturday, May 3<sup>rd</sup> and 4<sup>th</sup>, 2019 at the Crowne Plaza Hotel in Sacramento. The theme was “Build Your Own Toolbox for Self-Advocacy”. Tools are strategies, techniques, and

skills used to promote Self-Advocacy goals and objectives. The two-day conference featured two outstanding keynote speakers. Charlie Miller, of the Georgie Vocational Rehabilitation Agency, spoke on Friday about his self-advocacy journey and how he uses self-advocacy tools to advocate for himself and others as he works to create legislative systemic change in Georgia. On Saturday, our very own Kecia Weller of the Tarjan Center keynote with her speech “From Abuse to Recovery”.

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**(Continued from page 5: “Conference”)**

Kecia talked about how she uses the self-advocacy strategy “Think, Plan, Do” to achieve important goals in her life. The conference sessions covered a wide variety of topics and the different ways that people use self-advocacy in their lives.



SSAN Members lead sessions covering topics like CalABLE, Person Centered Planning, Statewide Networks and advocating for Competitive integrated employment at the 2018 AUCD Conference.

SSAN Member Lisa Cooley, led a session on the benefits of Cal ABLE.



SSAN Members led a session on their experience advocating in Washington, D.C.

SSAN Member Paul Mansell, led a session on Self-Advocacy and Person Centered Planning.

**Take-aways from some of the Presenters:**

“I attended workshops on self-determination, fighting for your health, regional and statewide networking on Friday, and people before politics on Saturday. On Saturday I gave a presentation on Self-Advocacy, **(Continue on page 7: “Statewide SA Conference”)**



**(Continued from page 6: “Statewide SA Conference”)** Disability Pride, and Person-Centered Planning. My presentation was well received, and I enjoyed giving it. I had the following take aways from the conference: Self-Advocacy is not just a California thing, it is nationwide thing. Self-Advocates need to have persistence, courage, and determination because others may not want to listen to us. Using strategies and techniques can help us become more effective Self-Advocates. Most importantly Self-Advocacy can be fun.”  
— Paul Mansell, San Diego.

“I presented with two other University Centers for Excellence in Developmental Disabilities (UCEDD) colleagues, Robert Levy and Wesley Witherspoon. Our presentation talked about our experiences at the Association of University Centers of Disabilities (AUCD) 2018 conference in Washington, DC. Our presentation talked about how each of us work at our own individual UCEDDs and why it’s important for other UCEDDs in the AUCD Network to hire Individuals with Intellectual/Developmental Disabilities to be on staff for their UCEDD. This is all supporting inclusion for Individuals with Disabilities inside the AUCD Network.

I had a fantastic time at the May 2019 Self-Advocacy conference in Sacramento. I’ve never been to this particular Self-Advocacy conference before and I’m really pleased with how Supported Life Institute supports Self-Advocates by producing the May Self-Advocacy conference.” — Kecia Weller, UCLA Tarjan Center.

“I enjoyed meeting advocates from across California and even Nevada.” – Wesley Witherspoon, USC Children’s Hospital.

“I thought that it was neat to see clients and staff from across California. I wish I could have gone to more sessions, especially the ones given by Jackie Armstrong, who presented about her dream job, Charles McCarron about living with Autism, and John Sanchez about owning small businesses.

I enjoyed presenting along with Kecia Weller and Wesley Witherspoon on our experience in Washington D.C. advocating for better access to Competitive Integrated Employment for people with disabilities.” — Robert Levy, UC Davis Mind Institute.



## **A New Service Transportation for Sacramento Regional Transit (SRT)**

**By Robert Levy UCD MIND Institute  
UCEDD**

Since April 2018, the Sacramento area, has been testing a new service as a part of the Sacramento Regional Transit (SRT) services. The service is now expanding throughout the Sacramento area. Starting on September 9, 2019 bus route 24 will be added to the RT smart on-demand ride service. The services will mainly affect the cities of Orangevale and Fair Oaks. This service will be door to door service just like a taxi, Uber and Lyft or Super Shuttle (if going to the airport). The service will operate using a phone app (like Uber or Lyft). Once you download this app on your phone you have to put your email address in to create an account. Once you create an account, you can go on your phone under booking available put your pick-up location and then put your drop off location. After that go to request ride then press confirm. If you want to cancel your ride, press options and click under cancel a ride request. One downside is that it doesn't set up rides far in advance, it has to be on the

same day and the close to the time you want to get your ride. If you want to know more about this RT Smart on-demand ride service here are two links:

To learn how to use the app:

[https://transloc.wistia.com/medias/9yz\\_eu41vrc](https://transloc.wistia.com/medias/9yz_eu41vrc)

For information from SRT visit:

<https://www.sacrt.com/apps/smart-ride/>

These 2 two links should help the community learn more about the new service RT On-Demand Ride and how it works on your phone. Once you are all set up, you will be ready to go wherever you need to go on your daily life.



## Long and Winding Road

By Paul Mansell

I have the good fortune of being selected to be a participant in the role out of the Self-Determination Program. I have been involved in Self-Determination behind the scenes as a Board Member and as an employee for over 20 years, and hearing that DDS picked me was a dream come true. As I go through the SDP process I am mindful how experimental the whole thing is, so I can both learn as much about it as I can and help educate SDRC staff and the community about all the twists and turns of the SDP.

I want with all my heart to be successful in the SDP because all my life I have had issues of failure and powerlessness.

Growing up, I rarely felt like I fit in. I was not athletic and was often picked last to be on a sports team. It did not help that at age 6, I started wearing glasses and was teased for it. Despite my efforts to succeed academically, I never reached the honor roll and I just was a B student— that hurt.

Not being able to drive because of my epilepsy, has also contributed to feeling like an odd man out.

My differences made me feel like a failure growing up and I developed a sense of helplessness. I became dependent on others to get things done or to show me the way. Becoming skilled at writing changed my life, redefining how I see myself, interact with others, and lead my life. It has helped me to redefine how I see life and I have started looking at opportunities as pathways for success and accomplishment. I still get bogged down with negative thoughts saying I am no good, but now I have evidence to counter those thoughts. This makes a world of difference to me.

Everything these days is so goal and objective driven, that it can be easy to miss the small moments and appreciate the simple things in life.

We may be so busy trying to see the big picture, that we miss the rose buds at our door as we rush out to the car for our daily commute. We may be so busy wolfing down lunch, that we don't even notice the taste or chat with a co-worker.

This tunnel vision can be productive and efficient and has utility, but at what cost?

**(Continue on page 10: “Windy Road”)**



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I suggest that we put the brakes on all this busyness and doing, pause, take a breath, and simply be present in the moment.

I confess I suffer severe tunnel vision and I get focused on the destination and nothing else matters. But now I am in the Self-Determination Program and everything matters.

Everything is so experimental, it is all an adventure. The destination of the SDP may be living a satisfying, productive, and meaningful life in the community, but that leaves out a whole lot—the steps along the way. It leaves out the Orientation, the Person Driven Plan meeting, the crafting of the spending plan, selecting my service supports, and then and most importantly living out the plan on a daily basis.

My daily work life includes going into the office, turning on my computer, checking my emails and voice mails, and then going on my social rounds.

My day concludes with a commute home, a bottle of Non-Alcoholic Beer, sending off some emails, listening to my favorite tunes— usually the Beatles,

dinner, and bed. Frequently, I write a list of each and everything I am grateful for this day.

After I write the list, I read the list, and in so doing lift my spirits of the day. This is a day wonderfully made, and if I repeat them day after day I will have a wonderfully made work week, and I am ready for the week end.

I conclude this article urging you to enjoy the peripheral, visit the fringe of life, climb out of your ruts and frequent the edge of life. This is what brings novelty to life and keeps you young at heart. Destinations are important and sooner or later we will get there, but let’s remember to experience the footfalls of the present along the way on the long and winding road.

## Disability and Aging Capitol Action Day Recap

By Renee Wooten, CFILC Representative



I recently had a chance to sit down with one of the organizers of Disability and Aging Capitol Action Day (DACAD), Allie Cannington, to get a better understanding of what was involved in the planning of the event.

### What is DACAD?

Disability Capitol Action Day (DCAD) only cross-disability event at the California State Capitol held each year. DCAD is put together by the Disability Action Coalition. It is a day where people with diverse disabilities and allies educate legislature. This year marked the 15<sup>th</sup> anniversary for DCAD.

This year the Disability Action Coalition partnered with the California Alliance for Retired Americans to organize the 1<sup>st</sup> Disability and Aging Capitol Action Day (DACAD).

### What was the schedule for the Day and what happened at each event?

The event started at Cesar Chavez Plaza with a Resource Fair and Educational Rally. We had around 35 Resource tables with rich information from organizations and programs that support people with disabilities and the aging community. There was a rally at the park to serve as an opportunity for the community to tell their stories about the services and supports they use. The event also featured a performance by Kendra Diana local singer/song writer and a local high school dance crew with people with diverse disabilities and allies. People could sign up on site to be a part of teams that were conducting visits to members of the state legislature. At 11:30 attendees marched to the steps of the capitol with their signs and singing chants.

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Lunch and legislative briefings took place at the Capitol. People then met with members of the legislature in teams to educate them on the joint policy platform and the issues that are important to members of the disability and aging community.

**What was your favorite part of the event?**

There were over 1,300 people who participated in DACAD this year. It was a big success. My favorite part of the event was having one place where people of all types of disabilities came together to advocate for the services and supports that are important to them. The theme for this year was “Unity through Diversity”, which was reflected through the people that turned out for the event.

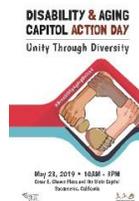
**What would you like to do differently next time?**

This was my first year organizing this event, and I learned a lot from the experience. For next year’s event, I would like to see more shared leadership in the planning process, more involvement from members of the Disability Action Coalition. I am

thinking that it might be good to coordinate the legislative team visits at least 2 weeks before the event, to make sure that everything runs smoothly. I am also thinking about doing more fundraising to have more people to be able to participate. I also want to look into better ways for people to participate remotely, for those who cannot travel.

**How did you learn about your organizing skills?**

I had a little bit of training, but I have learned a lot by asking questions. I have learned from my mistakes, as sometimes that is the easiest way to learn. I would like to organize a future training on community organizing, as a way to encourage more people to become leaders within their communities.



Check out the Disability Action Coalition website for more information:

[Disability Action Coalition](http://DisabilityActionCoalition.org).



## **Interview of Robert Levy**

As a follow-up to the last edition of *Voices of SSAN*, Wesley Witherspoon interviewed Robert Levy, the SSAN Representative from UC Davis MIND Institute.

### **How do you manage 3 jobs?**

I currently have three jobs, working at Target, Progressive Employment Concepts (PEC) and UC Davis Mind Institute. I work four days a week. I manage to get to work on time with the help of coworkers like Steve Ruder, who helps to support me at the UC Davis Mind Institute. I also have my coworkers help me to manage to get the work done that is necessary. I make sure to communicate with my supervisors and request vacation in a timely manner. Working with support staff like job coaches is helpful to me. On Tuesdays I work at both Target and PEC. I have good relationships with my employers and they are understanding and flexible about my schedule.

### **How does it feel to be a national advocate for people with disabilities?**

It feels good to be able to tell people across the country about the impact of SSAN in improving the lives of people

with disabilities in California and think of the possibility of creating and supporting groups in other states. It is important for people to know about the services and supports that are necessary for people with disabilities to be successful. I am proud that in 2017, I testified to the US House of Representatives on the needs of people with disabilities and the importance of funding day programs. Without day programs people with disabilities will stay home and not be productive. I presented at the AUCD Conference on what I do for UCEDDs. This was a great opportunity to talk to people about the importance of employing people with disabilities within the UCEDD system.

### **What do you want people with disabilities to know for the future?**

Start talking about your disability early. Talk to your parents and family about the future. As a grown-up get support from other agencies besides the regional center. Family and friends can help you to identify your interests and set goals to help you to achieve your goals. Work with support staff to develop goals for your future and strategies for helping to manage your disability future planning. **(Continue on Page 14: "Interview")**



**(Continued from page 13: “Interview”)**

Goals should have time limits with them like 6 months, this will help you to stay on track and keep moving forward. Once you succeed on one goal, you can work on more goals and progress in life. Growing up, my family, especially my sister, supported me in identifying my interests and setting goals to help me achieve them.

**What are some of the benefits of being involved with SSAN?**

We get to work as a team. There are 20 members across the state. We go out in the community and talk about self-advocacy. SSAN helps members to develop self-advocacy skills. SSAN is all about collaborating with other leaders across the state and letting people know about what is important to Self-Advocates in California.

**Anything else you want people to know about?**

People should know what SSAN does and what the purpose of SSAN is. People should also know about the work of the State Council. People need to know about the different local self-advocacy groups and the organizations

and departments that support self-advocacy in California, some of which have representatives on SSAN. Self-advocates are involved with family resource centers, that are through the regional centers. People should know about the different strategies that are available to help people with disabilities to succeed, like supported decision making and the different local resources available across the state. For example: independent living centers, Disability Rights California, Regional Advisory Committees, Regional offices of the State Council and other resources are available to help in the transition process.



## SSAN Members

- Nathaniel Florez – North Coast
- Teresa Moshier – North State
- Lisa Cooley – Sacramento
- Chen Curtiss – North Bay
- Regina Woodliff – Bay Area
- Robert Balderama – North Valley Hills
- David Forderer – Central Coast
- Rebecca Donabed – Sequoia
- Julie Gaona – Los Angeles
- Sean Sullivan – Orange County
- Daniel Fouste – San Bernardino
- Paul Mansell – San Diego Imperial
- Desiree Boykin – ARCA
- Renee Wooten – CFILC
- Nicole Patterson – DDS
- Scott Barron – DRC
- Robert Levy – UC Davis Mind Institute
- Kecia Weller UCLA Tarjan Center
- Wesley Witherspoon – SCDD and USC Children’s Hospital

## Learn About SSAN Partners

- [Association of Regional Center Agencies](#)
- [California Foundation for Independent Living Centers](#)
- [Department of Developmental Services](#)
- [Disability Rights California](#)
- [University of California, Davis MIND Institute](#)
- [University of California, Los Angeles, Tarjan Center](#)
- [University of Southern California, Children’s Hospital](#)



## SAVE THE DATES

33<sup>rd</sup> Annual Supported Life Conference

**“Opening Doors to Diversity:  
Cultivate...Participate..Celebrate”**

**When:** October 10-11, 2019

**Where:** Crowne Plaza Northeast  
Sacramento

**More Info:** [Supported Life Institute](#)

3<sup>rd</sup> Annual Independent Living  
Conference

**When:** October 9, 2019

**Where:** Great Wolf Lodge  
Garden Grove, CA

**More Info:** [Independent Living  
Conference](#)

**Contact your regional office of the State  
Council on Developmental Disabilities  
for information on trainings happening  
in your area.**

## SSAN Kudos Corner

Paul Mansell takes his job representing San Diego Imperial Regional Office on the SSAN to heart. He is the kind of member that is always thinking of ways to strengthen and encourage the SSAN. He is always willing to share his knowledge with the SSAN, as he learns along the way, to help people with disabilities. He is committed to the vision of the SSAN to invite new partners to the table, and to work with the youth to help grow the leaders of tomorrow. Paul is easy to talk to and is ready to do whatever is needed to get the job done. Paul, thank you for your passion and commitment as the Chair of the Legislative Workgroup. The SSAN would not be the same without you. Kudos to you!!

## Self-Determination Update

Check out the latest [DDS Self-Determination Newsletter](#) for the latest on California's Self-Determination Program.